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Parental Presence and the Impact of Antiretroviral Treatment on Household Composition in Khayelitsha

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CSSR Working Paper No. 318
December 2012

Published by the Centre for Social Science Research
University of Cape Town
2012

http://www.cssr.uct.ac.za

This Working Paper can be downloaded from:

http://cssr.uct.ac.za/pub/wp/318/

ISBN 978-1-77011-272-8

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Abstract

AIDS (the Acquired Immune Deficiency Syndrome) is known to affect household structure in Africa, as patients rely on kin (especially mothers) for care and support. Little is known about how highly active antiretroviral treatment (HAART) might reverse these dynamics. We use panel survey data from Khayelitsha (Cape Town) to explore changes in the presence of mothers, fathers, sisters and sexual partners in HAART patient households over time. We show that HAART patients, when they first started treatment (i.e. were sick with AIDS), were more likely to be living with their mothers and in parent-headed households than their counterparts in the general population (that is, a sample of Khayelitsha residents and matched to HAART survey respondents by age, gender and education). Over time, the presence of mothers, fathers and parental household heads drops significantly and the living arrangements of HAART patients become indistinguishable from those in the matched sample in this respect. This is consistent with the hypothesis that parental support is no longer required once HAART restores health, thereby enabling patients to live independent, healthy lives. We also show that over time there is a marked increase in the proportion of HAART patients with sexual partners resident in the household. However, the proportion remains significantly lower than for their counterparts in the general population, and HAART patients are more likely to live in single-person households. This suggests that HIV-positive people continue to suffer from social marginalisation to some extent, even after being stabilised on treatment.

Introduction

There is evidence that Africans suffering from the Acquired Immune Deficiency Syndrome (AIDS) rely on kin, especially parents, for care and support when they are very ill, but there are no studies exploring whether these dynamics are reversed by highly active antiretroviral therapy (HAART). We contribute to filling this lacuna by using two panel surveys from Khayelitsha, an African township in Cape Town, to explore changes in key aspects of living arrangements for HAART patients and whether these are significantly different to people of similar age, gender and education in the general population.

We find that HAART patients, when they were sick with AIDS, were more likely to be living with their mothers, fathers and sisters than was the case for a comparison sample of Khayelitsha residents matched to the HAART patients by age, gender and education. They were also more likely to be living in parent-headed households. Over time, however, HAART patients were able to alter their living arrangements such that the presence of mothers, sisters and parental household heads became indistinguishable from that in the general population. We also find that the number of HAART patients with sexual partners rises over time, but that compared with the matched comparison sample, they were more likely to be living alone and without sexual partners. Our study thus reinforces findings from the qualitative literature about the importance of kin, especially mothers, in providing support to people with AIDS. However, we are able to go beyond the existing literature by showing that HAART can reverse some of these dynamics, but people living on HAART remain more socially isolated in several respects.

Parental Presence and Care: Evidence from the Literature

We know that terminally ill young South African adults often return to the parental home in order to access care and support, primarily from their mothers (e.g. Bachman and Booysen, 2006; Clark *et al,* 2007; Shatz, 2007; Welega *et al,* 2009). As Haour-Knipe (2009: 44) points out, this is to be expected in developing countries where extended family serves as the 'primary social safety net'. Indeed, the effect of AIDS on living arrangements and the burden of care are not unique to South Africa. A Ugandan study found that elderly parents, especially mothers, were the main care-givers for people living with AIDS (Ssengonzi, 2007) and similar dynamics have been reported in Thailand (Knodel and Van Landingham, 2003). But what sets Southern Africa – and especially South Africa – apart is the generally lower presence of fathers and the

importance of 'uterine kin' (mothers, grandmothers and sisters) in providing stability and care (Preston Whyte, 1978; Denis and Ntsimane, 2006: 242; Harper and Seekings, 2010).

This is a consequence of South Africa's history of oscillating migration and apartheid, which separated families geographically, often for long periods of time. But it is also a consequence of declining rates of marriage to the point that it is no longer the norm (Seekings, 2011). Hunter (2006; 2007; 2010) argues that the rise of unemployment was the key factor behind this decline, as only the relatively well-off African men could afford to pay *ilobolo* (bridewealth) or act as reliable providers for their families. Under these circumstances, women are incentivised to form looser connections with men (sometimes several men) and closer bonds with siblings and mothers.

The phenomenon of the 'absent father' has been well documented in urban and rural areas (e.g. Morrell and Richter, 2006; Hosegood *et al,* 2009; Bray *et al,* 2010). What this means in terms of the supporting role of fathers, however, is unclear. According to Morrell and Richter (2006: 6), paternal absence implies a lack of fatherly support for children's care. But other research emphasises that many fathers maintain meaningful contact with children, even when they do not reside in the household (Denis and Ntsimane, 2006) and that their role in providing care when they are in the household often goes unreported (Montgomery *et al,* 2006; Hosegood and Madhavan, 2010). We thus explore trends in the presence of fathers and mothers in our analysis below.

Methods: The Khayelitsha Panel Studies

Khayelitsha is a peri-urban settlement of about half a million predominantly Xhosa-speaking residents approximately 30 kilometres outside of Cape Town. Almost half of working age adults are without jobs and over a quarter of pregnant women are HIV-positive (Hodes and Naimak, 2011; Boulle *et al*, 2010; MSF *et al*, 2011). In 2000, Médecins Sans Frontières (MSF), in partnership with the Western Cape provincial government, set up three clinics in Khayelitsha with the sole purpose of providing HAART to treat AIDS. This was South Africa's first public sector provision of HAART – deliberately located in an African township to demonstrate that HAART could be provided in resource-poor settings.

Between 2001, when the MSF HAART pilot programme was established, and 2008, more than 10,000 people were successfully initiated on HAART with over 93% retained in care (MSF *et al*, 2008: 1). The number of patients started on HAART per month increased from less than 10 in 2001 to 465 in 2010 (MSF, *et*

al, 2011). As of 2008, about a third of all adults on HAART in the Cape Town metropolitan area were being treated in Khayelitsha (MSF *et al*, 2008: 1).

In 2004, 242 Khayelitsha HAART patients were recruited into a panel study conducted by the AIDS and Society Research Unit at the University of Cape Town. They were recruited through social networks, clinic support groups and word of mouth; hence the sample cannot be regarded as strictly representative. However, as two-thirds of the starting HAART cohort was recruited into the study, the sample can be regarded as broadly representative of the experience of early HAART patients then stabilised on treatment (Venkataramani *et al,* 2009).

The first round of the survey (wave 1) was conducted in 2004 and a second wave followed in 2006. Retrospective questions were asked of respondents about their households and health at the time they started HAART, thereby allowing us to construct a retrospective 'wave 0' (i.e. at the time of HAART initiation) for all respondents. Clinical data was not collected but retrospective questions about perceived health are strongly suggestive of the restorative impact of HAART. Respondents were asked to rank on a 10-point scale (with ten being the best health they have ever experienced) their current health status, as well as their recollections of their health at the time they initiated HAARTand then their health at three and six months later.

The mean score for health at HAART initiation was 2.8 (standard deviation: 2.2), three months later it was 5.3 (standard deviation 2.0), six months later 7.8 (standard deviation 1.7) and at the time of the interview it was 9.5 (standard deviation 1.0). This steep increase in perceived health status mirrors the steep increase in clinical markers like CD4 counts that have been observed in the Khayelitsha cohort (Boulle *et al*, 2010) and in their quality of life (Hughes *et al,* 2004) and hence can be regarded as a reliable indicator of improved health. The fact that employment increased significantly (from 31% in wave 0 to 50% in wave 2) as did job search (from 8% to 18%) over the same period is also strongly indicative of improved health following the initiation of HAART. Similar economic effects of HAART have been documented in other studies and attributed to the effect of antiretroviral treatment on clinical and perceived health (e.g. Coetzee, 2008; Coetzee and Nattrass, 2004; Rosen *et al,* 2010).

Table 1: Attrition analysis (dependent variable: 1 = attritor, 0 = in full panel study)

	Characteristics		**Univariate probit coef. (95% conf)**	**Multiple regression:** **Probit coef** **(95% conf interval)**		
	Attritor	**In panel**				
Age	38 years	33 years	0.04*** (0.02-0.07)	0.04** (0.01 0.07)	0.04** (0.01 0.07)	0.04** (0.01 0.07)
Years of schooling	8.5	9.7	-0.07** (-0.13 - 0.01)	-0.03 (-0.10 0.04)	-0.01 (-0.08 0.06)	-0.02 (-0.09 0.06)
Female	75%	80%	-0.17 (-0.62 0.28)	-0.01 (-0.46 0.49)	-0.02 (-0.50 0.47)	-0.06 (-0.55 0.45)
Worst health ever at HAART start	39%	40%	0.03 (-0.35 0.42)	-0.08 (-0.49 0.31)	-0.01 (-0.44 0.42)	-0.04 (-0.47 0.40)
Working	18%	37%	-0.54** (-0.99 - 0.09)		-0.47** (-0.93 0.00)	-0.40 (-0.90 0.11)
Disability grant recipient	83%	72%	0.33 (-0.13 0.80)		0.31 (-0.20 0.82)	0.241 (-0.29 0.77)
Per capita household income	R487	R630	-0.00 (-0.00 0.00)			-0.00 (-0.00 0.00)
Mother in household	19%	23%	-0.16 (-0.61 0.30)			0.16 (-.95 1.27)
Father in household	5%	5%	-0.09 (-0.94 0.76)			0.08 (-0.93 1.10)
Parent-headed household	16%	22%	-0.21 (-0.69 0.26)			-0.18 (-1.39 1.04)
Partner in household	19%	32%	-0.40* (-0.84 0.04)			-0.31 (-1.80 0.17)
Pseudo R2				0.055	0.081	0.088
N				242	242	234
Prob>chi2				0.018	0.007	0.064

***p<0.001; **p<0.05; *p<0.1

The HAART panel study has an attrition rate of 16% (of the 242 respondents interviewed in 2004, only 202 were present for all subsequent interviews), thus raising the potential for attrition bias to skew our results. Table 1 shows that older respondents in wave 1 were more likely to attrite from the panel study, but that the effect was small; for each additional year of age, the probability of attrition rises by 4 %. More worrying is the fact that those without jobs were more likely to attrite, since being employed cut the probability of attriting by half). However, this was significant only in univariate analysis. Once household income and other household characteristics are controlled for, the effect of being employed becomes statistically insignificant. Having a resident sexual partner reduces the probability of attrition by 40 % in univariate analysis, but this effect also becomes statistically insignificant once other factors are controlled for. In other words, there appear to be no systematic drivers of attrition beyond the (small) effect of age once a multivariate analysis is conducted, and the explanatory power of the regression models remains low in all specifications. This suggests that attrition bias is not a serious problem, although we should bear in mind that those with more economic and social support in wave 1 were more likely to remain in the sample than those without work or without a live-in sexual partner.

The HAART panel study allows us to explore changes in household characteristics of HAART patients over time, but we also need to know how this compares to households in the general population. We thus constructed a 'quasi control' data set drawn from a survey of Khayelitsha residents conducted in parallel with the HAART panel study, which can be regarded as representative of adult African Khayelitsha residents (Magruder and Nattrass, 2006). From this data set we then drew a sub-sample of 202 respondents matched (using a probit regression) by age, gender and education to respondents in the HAART sample.[1] The result is a matched and balanced panel data set of HAART patients and Khayelitsha respondents with almost identical average age, gender and educational profiles (see Table 2). That four fifths of respondents are women is in line with the demographics of the African AIDS epidemic and the fact that disproportionately more women than men access HAART programmes (Nattrass, 2008).

[1] The matching process was done by Nicoli Nattrass, Celeste Coetzee, Takwanisa Machemedze and Catherine Jury.

Table 2: The matched data sets (standard deviation in parentheses where appropriate)

	HAART	Khayelitsha Matched Sample
% Women	80.2%	79.7%
Age (wave 1)	33.2 years (6.5)	33.6 years (7.4)
Years of education (wave 1)	9.7 (2.8)	9.9 (2.5)
Total (n)	202	202

Results: Changes in Household Characteristics Following the Initiation of HAART

As discussed earlier, there is a body of evidence pointing to the role of 'uterine kin', especially mothers, in caring for adults suffering from AIDS. Assuming that HAART restores health and independence, we would thus expect changes in household characteristics as a consequence of the HAART rollout, especially where mothers and sisters are concerned. Therefore, we hypothesise that mothers and sisters were more likely to be present in the households of HAART respondents when they were sick with AIDS (i.e. when they initiated treatment) than when they became long-term HAART patients. Table 3 shows that this was indeed the case: maternal presence dropped significantly from 31% to 19% between wave 0 (when HAART was initiated) and wave 2. Indeed, by wave 2, there was no significant difference between maternal presence in HAART-patient households than in the matched sample of Khayelitsha residents. The trend was similar and also statistically significant for households with no mother but a sister present. In other words, the data are consistent with previous research on the importance of mothers and sisters as carers of people living with AIDS, but we are able to go beyond the available literature by showing that HAART relieves them of some of this burden.

Table 3: The presence of mothers, sisters, fathers and parent-headed households

	HAART start (wave 0)	**HAART (wave 2)**	**Khayelitsha (wave 2)**
Mother present in the household	62 (30.7%)	39 (19.3%)	43 (21.3%)
Testing the statistical significance of the difference between wave 0 and wave 2 of the HAART sample	Pearson chi^2=93.58, p=000***; Fisher's exact: 0.000***		
Testing the statistical significance of the difference between wave 2 of the HAART and Khayelitsha samples		Pearson chi^2=0.24, p=0.621; Fisher's exact: 0.711	
No mother but at least one sister in the household	40 (19.8%)	30 (14.9%)	26 (12.9%)
Testing the statistical significance of the difference between wave 0 and wave 2 of the HAART sample	Pearson chi^2=48.73, p=0.000***; Fisher's exact: 0.000***		
Testing the statistical significance of the difference between wave 2 of the HAART and Khayelitsha samples		Pearson chi^2=0.33, p=0.565; Fisher's exact: 0.666	
Father present in the household	15 (7.4%)	9 (4.5%)	19 (9.4%)
Testing the statistical significance of the difference between wave 0 and wave 2 of the HAART sample	Pearson chi^2=48.09, p=000***; Fisher's exact: 0.000***		
Testing the statistical significance of the difference between wave 2 of the HAART and Khayelitsha samples		Pearson chi^2=3.84, p=0.050*; Fisher's exact: 0.076*	
Parent-headed household	60 (70.3%)	35 (17.3%)	42 (20.8%)
Testing the statistical significance of the difference between wave 0 and wave 2 of the HAART sample	Pearson chi^2=84.57, p=0.000***; Fisher's exact: 0.000***		
Testing the statistical significance of the difference between wave 2 of the HAART and Khayelitsha samples		Pearson chi^2=0.79, p=0.375; Fisher's exact: 0.447	

***p<0.001; **p<0.05; *p<0.1

Table 3 also reports an analysis of changes in paternal presence. We find that fathers, as expected, are generally less present than mothers, both in the HAART sample and in the matched Khayelitsha survey. But like maternal presence, fathers were significantly more likely to be in the household when HAART respondents were sick with AIDS than later (wave 2). Whether they were actively playing any caring or support role cannot be ascertained from the data.

Interestingly, by wave 2 there were statistically significantly fewer fathers in HAART-patient households than in the matched comparative sample.

Another limitation of the data set is that we do not know whether parents were present in the household as carers/supporters or as dependents of HAART patients. Hence, we conduct a further set of tests, checking whether the respondent was living in a parent-headed household, our intuition being that if the parent is declared to be the head of the household by the respondent, then it is likely that it is the respondent who is getting the care rather than providing for the parent. Table 3 shows that our results are very similar to those for mothers in the household: parent-headed households decreased significantly from wave 0 to wave 2 in the HAART sample and there was no statistically significant difference between the HAART and Khayelitsha households in terms of parent-headed households by wave 2.

Table 4 shows that there was a statistically significant increase between wave 0 and wave 2 in the number of HAART respondents who were heads of their households. In fact, more than half of the respondents in the HAART sample were household heads by wave 2. This is consistent with the hypothesis that the health-restoring effects of HAART promote greater independence for people living with HIV. However, there may also have been push factors at work – for example, some HAART patients may have been forced or encouraged to leave by other household members once they were able to take care of themselves. The fact that there were statistically significantly more single person households in wave 2 compared to wave 0 of the HAART sample – and compared to wave 2 of the KPS sample – is consistent both with HAART patients exercising greater independence *and* potentially experiencing persistent stigma and subsequent social isolation.

Table 4: Respondent-headed and single-person households

	HAART (wave 0)	HAART (wave 2)	Khayelitsha (wave 2)
Respondent as head of household	65 (32.2%)	110 (54.5%)	85 (42.1%)
Testing the statistical significance of the difference between wave 0 and wave 2 of the HAART sample	Pearson chi^2=55.37, p=000***; Fisher's exact: 0.000***		
Testing the statistical significance of the difference between wave 2 of the HAART and Khayelitsha samples		Pearson chi^2=6.20, p=0.013**; Fisher's exact: 0.017**	
Single-person households	8 (4%)	17 (8.4%)	7 (3.5%)
Testing the statistical significance of the difference between wave 0 and wave 2 of the HAART sample	Pearson chi^2=9.14, p=0.002**; Fisher's exact: 0.021**		
Testing the statistical significance of the difference between wave 2 of the HAART and Khayelitsha samples		Pearson chi^2=4.33, p=0.038**; Fisher's exact: 0.056*	

***p<0.001; **p<0.05; *p<0.1

There is evidence to suggest that HIV stigma, rather than falling as a result of the HAART rollout, actually rose in the early to mid-2000s. Using data from the Cape Area Panel Study of young adults, Maughan-Brown (2010) found that AIDS stigma increased in the African population between 2003 and 2006 and that fear of infection was the key driver. We hypothesise that the presence of sexual partners in the households of HAART patients is likely to increase over time as health is restored, but that in the context of ongoing AIDS stigma and fear of infection, HAART patients are less likely than their counterparts in the general population to be living with a sexual partner. As shown in Table 5, we find that there was indeed a statistically significant increase in the number of HAART patients with resident sexual partners, but that this remained significantly lower than was the case for their counterparts in the general population.

Table 5: The presence of sexual partners in households

	HAART (wave 0)	**HAART (wave 2)**	**Khayelitsha (wave 2)**
Partner present in the household	22 (10.9%)	69 (34.2%)	94 (46.5%)
Testing the statistical significance of the difference between wave 0 and wave 2 of the HAART sample	Pearson chi^2=12.71, p=000***; Fisher's exact: 0.001**		
Testing the statistical significance of the difference between wave 2 of the HAART and Khayelitsha samples		Pearson chi^2=6.43, p=0.011**; Fisher's exact: 0.015**	

***p<0.001; **p<0.05; *p<0.1

Our preceding analysis shows that the household structure of HAART patients is indistinguishable from that of the matched sample when it comes to the presence of mothers and sisters and parent-headed households by wave 2. This is consistent with HAART-related improvements in health and the increased independence it facilitates for patients. However, the fact that HAART patients in wave 2 are more likely to live alone and less likely to have a sexual partner is suggestive of the continued presence of stigma against those living with HIV/AIDS. Further research focused on stigma experienced by these HAART respondents is required to draw more conclusive inferences about these findings.

Conclusion

This paper shows that HAART can break the cycle and reverse the dynamics of AIDS sufferers "returning home to die" (Clark *et al,* 2007). The declining presence of mothers and sisters (e.g. uterine kin) and parent-headed households is strongly indicative of the effect of HAART on restoring health and independence for young adults living with HIV. Indeed, our comparative analysis shows that HAART patient households become indistinguishable from those in the matched Khayelitsha sample with regard to the presence of uterine kin and parent headship. However, as HAART patients are statistically significantly less likely to have a resident sexual partner and more likely to be living in single person households than their counterparts in the general population, we caution that HAART patients are probably experiencing ongoing stigma and social isolation in this respect.

A limitation of this study is that the panel study of HAART patients may suffer from some attrition bias, in that age was positively related to the probability of

attrition and the employed, and those with partners in the household in wave 1 were more likely to stay in the panel study than those without jobs or resident sexual partners. However, as the statistical significance of these variables (with the exception of age) disappeared in multivariate analysis, overall attrition bias was unlikely to be a serious problem since it is not systematically and robustly related to characteristics relevant to our analysis. But even if it is the case that attrition in the HAART panel study is significantly linked to those who were more socially marginalised (those without jobs and sexual partners), this raises the possibility that our conclusion about ongoing social marginalisation might actually be understated.

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The Centre for Social Science Research

The CSSR is an umbrella organisation comprising four research units:

The **AIDS and Society Research Unit** (ASRU) supports innovative research into the social dimensions of AIDS in South Africa. Special emphasis is placed on exploring the interface between qualitative and quantitative research. Focus areas include: AIDS policy in South Africa, AIDS-stigma, sexual relationships in the age of AIDS, the social and economic factors influencing disclosure (of HIV-status to others), the interface between traditional medicine and biomedicine, the international treatment rollout, global health citisenship, and the impact of providing antiretroviral treatment on individuals and households.

The **Democracy in Africa Research Unit** (DARU) supports students and scholars who conduct systematic research in the following four areas: public opinion and political culture in Africa and its role in democratisation and consolidation; elections and voting in Africa; the development of legislative institutions; and the impact of the HIV/AIDS pandemic on democratisation in Southern Africa. DARU has also developed close working relationships with projects such as the Afrobarometer (a cross-national survey of public opinion in fifteen African countries) and the Comparative National Elections Project, which conducts post-election surveys over 20 countries across the world.

The **Sustainable Societies Unit**'s (SSU) mission is to explore the social and institutional dimensions of economic development and the interaction between human society and the natural world. Focus areas include: winners and losers in South African economic growth and the interplay between ecological and economic concerns. The SSU was previously known as the Social Surveys Unit and still works on a number of survey projects, including the Cape Area Panel Study.